Supplementary Material

Relative Meaningfulness and Impacts of Symptoms in People with Early-Stage Parkinson's Disease

Supplement A. Survey questions about Parkinson's symptoms asked prior to Symptom Mapping

1. Please describe the symptoms of Parkinson's disease that you experience.
   (Open response)

2. Of the symptoms you described, which are the most bothersome to you and why?
   (Open response)

3. Have the symptoms you find most bothersome changed over time? If so, how?
   (Open response)

Of the following symptoms that were measured by WATCH-PD, please rate how bothersome each symptom is to you on a scale of 0-10, with 10 being the most bothersome.

4. Shaking (tremors)

5. Slow movements

6. Difficulty walking

7. Difficulty with balance

8. Trouble with fine motor (example: buttoning your clothing)

9. Altered mood (depressed, anxious, hopeless)

10. Excessive sleepiness

11. Feeling tired or fatigued

12. Difficulty thinking in general
    12a. Difficulty concentrating
    12b. Difficulty remembering
    12c. Slow thinking

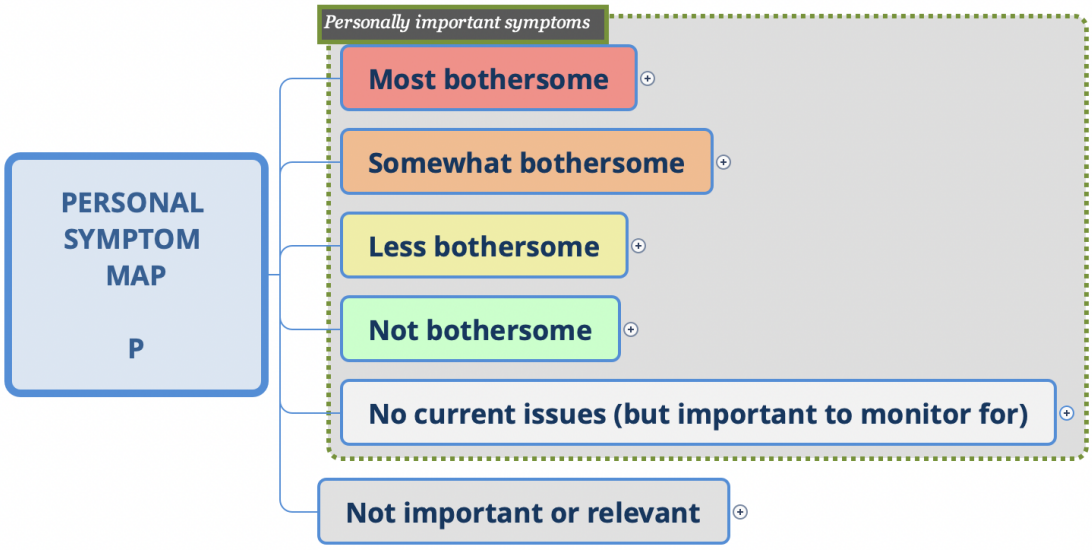
13. Difficulty speaking in general
    13a. Difficulty forming sounds (articulating)
    13b. Quiet speech
    13c. Monotone speech

14. Trouble with visual/spatial or depth perception (example: estimating distances)

15. Of these, which symptoms are the most important to you currently?
    (Multi select from list as above)

Supplement B. Symptom Mapping Semi-structured Interview Guide

1. First, would you tell me what Parkinson's disease-related symptoms you experience? From your responses on the survey, I see that you listed….
   [**Step 1 of the symptom mapping activity begins here.** As the participant directs, the interviewer will map the participants symptoms by order of personal importance.]

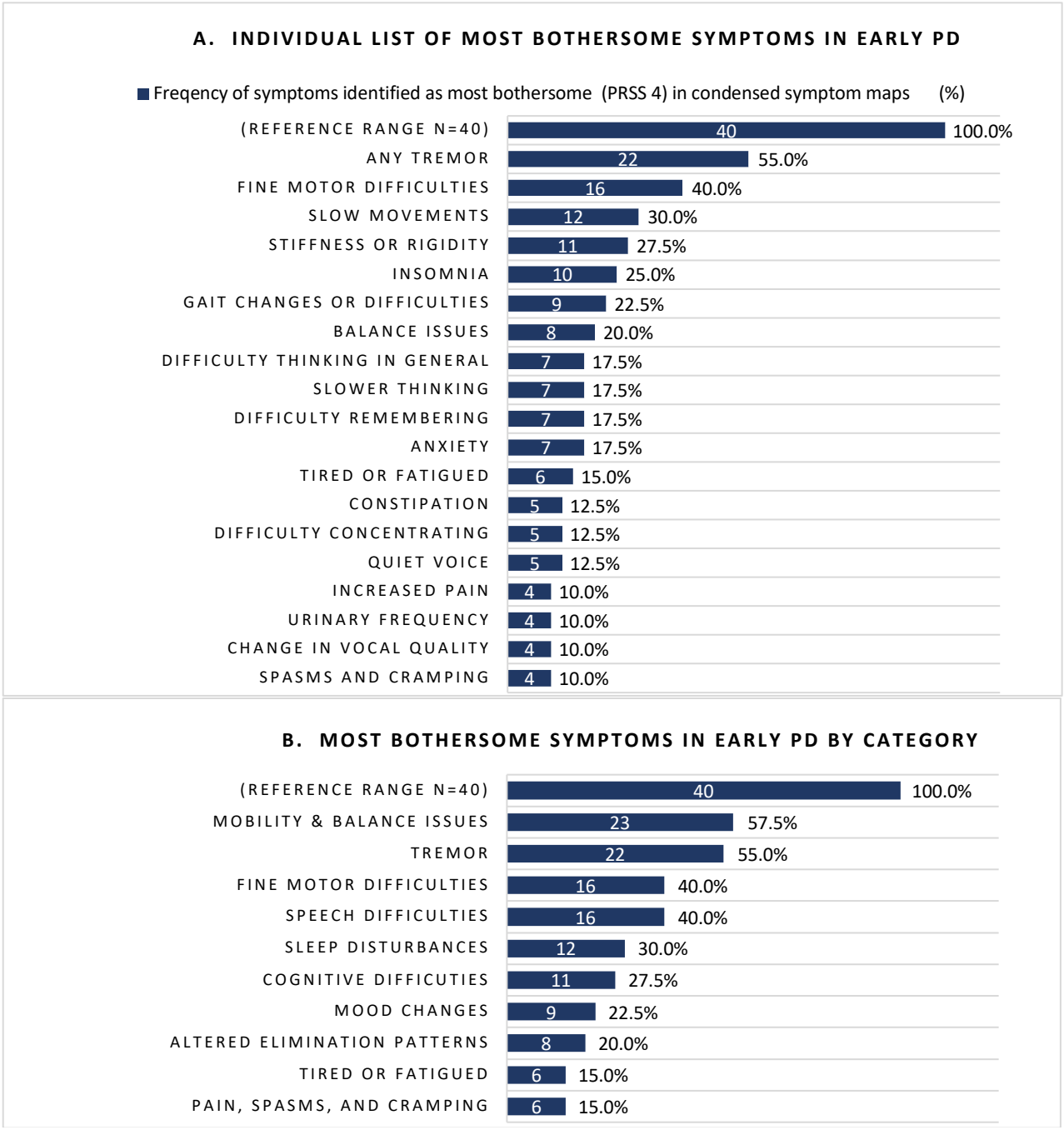


   - **Probe: Are there other symptoms that you experience that you have not told me about and that I don't have in your map?**
   - **Probe [*yes/no*] on any they do not spontaneously state (tremor, slow movements, gait disturbances, fine motor coordination, speech articulation, cognitive impairment, daytime sleepiness, mood symptoms).**
2. Of those symptoms you mentioned, explain to me which are the most bothersome to you. What specifically makes those symptoms bothersome, and in what situations? [The interviewer will add concise details to the symptom map delineating what makes specific symptoms important/bothersome. Example: if gait, is it foot lift or gait speed? Does it occur at home during regular daily activities or mostly when out exercising?]
3. Are the symptoms that are **most bothersome** also the **most important** to you, or is that different in some way?
   - **Probe: Have we captured all the symptoms that you experience correctly? Is there anything we missed?**

Supplement C. Quantitative coding schema for symptom maps

Map level (Node)	**PRSS**	**Description**
Most bothersome	4	Symptoms and impacts are present and most bothersome
Somewhat bothersome	3	Symptoms and impacts are present and somewhat bothersome
Less bothersome	2	Symptoms and impacts are present and less bothersome
Not bothersome	1	Symptoms and impacts are present but NOT bothersome
Not present	0	Symptoms and impacts are NOT present but are still personally important
Not relevant	.	Symptoms and impacts are NOT present and NOT relevant to early PD

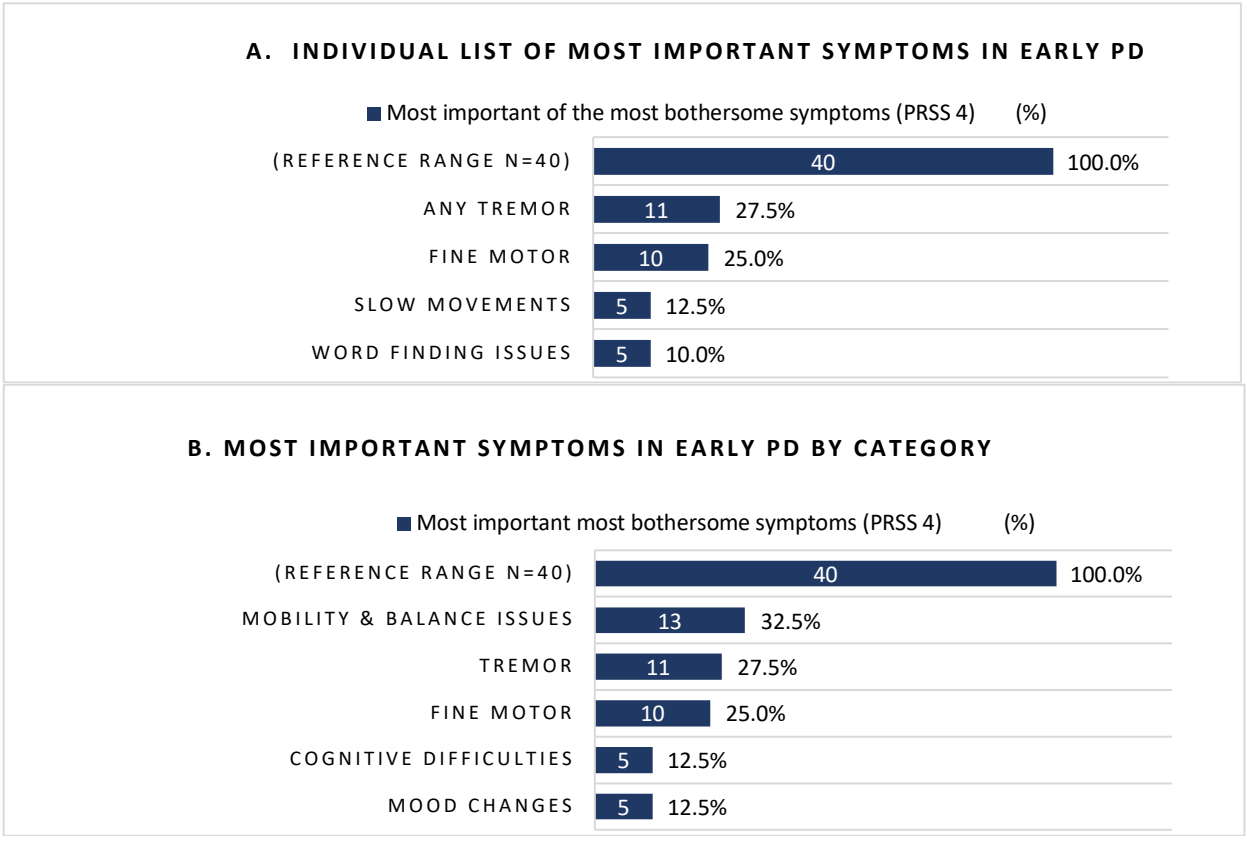
Supplement D. Comparison of most bothersome symptoms of early PD in symptom maps based on curation



Conceptual categories in graph B curated as follows:

a. Mobility & balance: slow movements, stiffness/rigidity, gait changes, balance issues, muscle fatigue, muscle weakness, decreased range of motion, altered arm swing, postural issues
b. Tremor: Hand/arm, Leg/foot, and Jaw/face/neck tremors
c. Fine motor: fine motor difficulties
d. Speech changes: quite voice, monotone voice, difficulty forming sounds (articulation)
e. Sleep disturbances: insomnia, disturbed/active dreaming, excessive daytime sleepiness, waking up to go to the bathroom
f. Cognitive difficulties: slow thinking, difficulty remembering, difficulty concentrating, word finding issues
g. Mood changes: anxiety, depression, frustration, apathy
h. Altered elimination: urinary frequency, constipation
i. Tired or fatigued: feeling tired or fatigued
j. Pain, spasms, cramping: pain, muscle spasms, muscle cramping

Supplement E. Comparison of most important symptoms of early PD in symptom maps based on curation



Participants identified an average of 1.78 "most important" most bothersome symptom; total number of "most important" symptoms is thus greater than the sample size of 40. Symptoms reported by <10% are not shown. Tremor combines: Hand/arm tremor (22.5%); face/jaw tremor (7.4% total; 75% of people experiencing symptom), and leg/foot tremor (5%)

Conceptual categories in the lower graph were curated as follows:

a. Mobility & balance: slow movements, stiffness/rigidity, gait changes, balance issues, muscle fatigue, muscle weakness, decreased range of motion, altered arm swing, postural issues
b. Tremor: Hand/arm, Leg/foot, and Jaw/face/neck tremors
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